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ABSTRACT

The report discusses findings and policy options of a study of technologies for handicapped individuals. An introductory section reviews definitions and demographic aspects of disabilities. Disability-related research and development is addressed in terms of the federal role and private sector involvement. Evaluation of technologies is said to be deficient and the need for a coherent, adequately funded evaluation program is needed at all levels of diffusion and adoption. Issues in resource allocation are briefly addressed. Policy options are set forth for five issues: (1) production, marketing, and diffusion of technologies; (2) involvement of disabled people and other consumers; (3) research, development and evaluation of technologies; (4) financial barriers to the use of technology, and (5) personnel issues. (CL)

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TECHNOLOGY AND HANDICAPPED PEOPLE

MAY 1982

Summary

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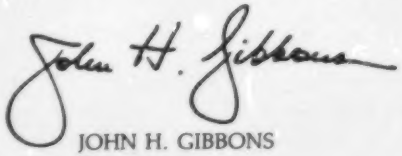
Foreword

Technology exerts a powerful influence over the lives of everyone, making life easier, more fulfilling, but sometimes more painful and frustrating. This statement is especially true for people with disabilities. The appropriate application of technologies to diminishing the limitations and extending the capabilities of disabled and handicapped persons is one of the prime social and economic goals of public policy.

The Federal Government is deeply involved in programs that affect the development and use of technologies for disabilities. Congress and other institutions have become increasingly interested in questions of how well programs that directly or indirectly develop technologies and support their use have been performing.

The Senate Committee on Labor and Human Resources requested the Office of Technology Assessment (OTA) to conduct a study of technologies for handicapped individuals. This summary presents the major findings and policy options of the full assessment report. The full report examines the specific factors that affect the research and development, evaluation, diffusion and marketing, delivery, use, and financing of technologies directly related to disabled people.

The study was guided by an advisory panel, chaired by Dr. Daisy Tagliacozzo. In addition, a large number of consultants, contractors, and reviewers contributed significantly. We are grateful for their many contributions. However, the content is the responsibility of the Office and does not necessarily constitute consensus or endorsement by the advisory panel or by the Technology Assessment Board.



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93-374 O - 82 - 2 : QL 3

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Technology and Handicapped People

Many people have significant limitations in their ability to perform one or more important life functions. These limitations either are present from birth or result from injury, disease, or aging. They often result in disability and, less often but still commonly, in handicaps. Whether a disability becomes a handicap depends on the interaction of the disabled person with the physical and social environments surrounding that person, and many other factors. Technology is one of those other factors. This report is about technology, handicaps, and the ways in which technology may be used to keep impairments from becoming disabilities and disabilities from becoming handicaps. It is about the processes involved in developing and distributing technologies and about the governmental and social role in directing those technological processes. The report's major conclusion is that **despite the existence of important problems related to developing technologies, the more serious questions are social ones—of financing, of conflicting and ill-defined goals, of hesitancy over the demands of distributive justice, and of isolated and uncoordinated programs.**

Photo credit: Barry Corbet. Courtesy of North American Reinsurance Corp.

Sports and physical activity are an important part of the lives of all people. Technologies, such as special wheelchairs or sound-emitting baseballs, are often used to allow the fuller participation of disabled people. Mary Wilson, shown above, believes that sports builds self-esteem and confidence, and improves attitudes toward and among disabled people

The influence of technology is felt in nearly every dimension of the lives of disabled people and in policies relating to disabilities. In some cases, technology is the cause of impairments, disabilities, and handicaps. Industrial accidents, adverse drug reactions, and automobile injuries illustrate this. In other instances, technology, especially medical technology, can eliminate or reduce impairments and keep them from becoming disabilities—e.g., knee implants and prescription eyeglasses. Furthermore, technology is used to facilitate "mainstreaming" in education, to prepare disabled people for employment or reemployment and to adapt the tasks and physical sites of jobs to the capabilities of disabled persons, and to create a controllable physical home environment. It is also used extensively to prevent disabilities from becoming handicaps—e.g., by making transportation systems and accommodations accessible. Technology enters the lives of disabled people in ways that people without disabilities may consider mundane—e.g., in the form of special utensil attachments or uniformity of traffic light bulb placements. Yet even these uses of technology are far from mundane. They may fulfill important needs and, when applied appropriately, may make life easier, safer, and more fulfilling for disabled and nondisabled people alike.

The state of technological capability in part determines what legislation and regulations are possible. It very clearly affects their implementation. Federal and State governments have created dozens, perhaps hundreds, of programs that relate to the "needs" of disabled persons. At the Federal level, with which this report is most concerned, there are programs (and agencies) for research, income maintenance, health care, education, transportation, housing, independent living, etc. It is important to understand the goals and operations of these programs, because not only are they affected by the state of technology, they in turn very much affect the development and use of technologies.

Increased attention is being focused on how to effectively and efficiently implement the laws and programs that are already in place rather than on the passage of additional laws or establishment of new programs. The volume, diversity, and often contradictory goals of many of the initiatives have tended to produce an administrative "gridlock," where movement of any kind, in any direction, is increasingly difficult.

The full report presents the results of a study requested by the Senate Committee on Labor and Human Resources. To support its broad responsibilities in the area of disabilities, the committee asked OTA to take a comprehensive look at the role played by technology in that area, identify technology-related problems, and suggest policy options for congressional consideration. The study concentrated on specific problems by examining the development and use of technology as a lifecycle process—a complex flow of ideas and technologies from conception, through research and development (R&D), through diffusion (including marketing where appropriate), to delivery and use.

STUDY BOUNDARIES

OTA uses a broad definition of technology: the practical application of organized bodies of knowledge. Such a definition covers both hardware and process technology. The present study, however, limits the definition of technologies, so that the focus is on technologies that are intended for and applied to individuals. Broader technologies, such as transportation systems, are covered in this report only in the context of program and societal-level examination of costs and benefits.

The study's involvement in certain disabilities and handicaps was tempered by pragmatism. For example, OTA tried to avoid becoming too involved with medical issues that are not substantially related to technology and to the functional disabilities that stem from chronic illness. Similarly, the aging process often carries with it a gradual lessening of functional abilities in various areas; such disabilities are covered, but only as part of the central theme of disabilities.

Prevention of impairments, disabilities, and handicaps is covered only briefly. The issues involved in a full-scale inclusion of prevention technologies (e.g., highway safety technologies, prenatal screening and diagnosis, diet) are of such magnitude that they deserve attention on their own. To illustrate some of the issues regarding prevention, a case study on passive restraint systems in automobiles is being issued separately as a background paper to the study.

SUMMARY

What constitutes an impairment, a disability, or a handicap? OTA's approach to definitional issues begins with the idea that society defines, implicitly, a population of people with "typical" functional ability. In contrast, society defines those who cannot perform one or more life functions within the broad range of typical as "disabled" or "handicapped."

There are many possible definitions of the terms "handicap" and "disability." Definitions are important, because they affect the methods for identifying, and actual identification of, people in need of assistance. OTA found that it is most accurate to use the phrase "having a disability" in describing a person with some type of functional limitation, given no specific background (contextual) information. A "handicap" has to be specified within its environmental and personal contexts. Disabilities and handicaps arise from impairments, which are the physiological, anatomical, or mental losses or "abnormalities" resulting from accidents, diseases, or congenital conditions. Generally, an impairment results in a disability when a generic or basic human function such as eating, speaking, or walking is limited. It results in a handicap when the limitation is defined in a socially, environmentally, or personally specified context, such as the absence of accessible transportation to take disabled people to work.

Technology for disabled people plays the role of improving the fit between individuals and their environments. By making a distinction between "disability" and "handicap," OTA is highlighting the necessity of studying both individuals and the environments in which they function.

Another critical issue, closely related to definitions, is that of demographics—the numbers and distribution of disabled or handicapped people. In large part because impairments and disabilities are not as objectively measurable as is desirable and because handicaps may change depending on their context, there is no dependable count of the number of disabled or handicapped persons. Nevertheless, considerable time is spent by researchers and various groups in making such estimates. Some of these estimates range as high as 45 million, including more than 10 million children. Typical lower range estimates are from 15 million to 25 million people.

Estimates of the number of people with disabilities are plagued by practical as well as conceptual problems. There is double counting of some people with more than one disability, underreporting of some disabilities (in part due to the stigma attached to being included on a list of disabled people), overcounting by organizations seeking to make a strong case for the extent of a particular disability, and incomplete counting of some disabled people, particularly those in institutions. A perhaps more important prob-

Photo credit: Provided to OTA by Pat Berilgen, Great Oaks Center, Silver Spring, Md.

This photograph shows Pat Berilgen assisting Danny Naylor in the use of a mercury head switch. The head switch activates the music on the tape recording when Danny holds his head in proper position. This training is used to give a person greater control over the use of muscles and nerves to position the head

lem with reported counts is that such counts usually do not take into account the severity of the functional impairment reported.

Basic to the development and use of appropriate technology are the procedures by which disabilities and handicaps are identified, goals for their amelioration established, and resources to meet the goals expended. The assessment and planning methods used under three Federal programs—vocational rehabilitation services, services for developmentally disabled persons, and special education services—are examined in the report in terms of their potential use in management information systems. The analysis discusses their effectiveness and efficiency in aiding or determining the appropriate use of resources for modifying handicapping and disabling conditions and for meeting the needs of actual participants.

Technology

One of the necessary conceptual bases for an examination of policies related to technology and disabled people is a framework of "appropriate application of technology."*

A technology may be considered appropriate when its development and use: 1) are in reaction to, or in anticipation of, defined goals relating to problems or opportunities in the disability area, 2) are compatible with resource constraints and occur in an efficient manner, and 3) result in desirable outcomes with acceptable negative consequences or risks to parties at interest.

The key to appropriate development and use of technologies lies in finding a compromise fit between: 1) the needs, desires, and capabilities of users and other relevant parties; and 2) the costs, risks, and benefits of technologies. Analyzing such a compromise may be relatively straightforward when, for example, deciding to prescribe or wear eyeglasses. In a case in which the disability in question is of the type for which technologies such as an artificial, myoelectric limb are being considered, however, the compromise decision process becomes extremely complex, and a framework for analyzing alternatives becomes very important. Factors, such as explicitly stating the goals of the technology's use, that should be part of a policy approach to appropriate use are presented in the full report.

The disability-related **research and development** system includes both public and private organizations: Federal, State, and local governments; individuals; companies; universities; special interest associations; and a number of other actors. The people that the system is intended to assist possess a broad range of handicaps and disabilities of varying severity. The technologies that the system produces cover an even broader range, both in type (including devices and process technologies or services), in sophistication, and in purpose.

*By "appropriate application of technology" OTA is not referring to the same concept as "intermediate technology" or "low-capital technology." Instead, the term refers to an informed sensitivity as to the conditions under which any particular technology is appropriately developed and, especially, applied.

93-374 O - 82 - 3 : QL 3

The Federal role in disability-related R&D has been steadily increasing in scope and magnitude, although it remains small in comparison to the number of people affected and the complexity of the research problems involved. The organizations expending the greatest effort, as measured by the size of their relevant R&D budgets, are the National Institute of Handicapped Research (NIHR), the Veterans Administration (VA), the National Institutes of Health (NIH), and the Office of Special Education. The National Aeronautics and Space Administration (NASA) is also involved in this area as a result of technology transfer efforts stemming from its primary mission. It collaborates with the above agencies to transfer new technologies evolving from its R&D base.

A recent survey conducted for NIHR found that the U.S. Government spends about $66 million a year on R&D related to technologies for disabilities. However, the U.S. Government also spends about $36 billion a year to support the income of disabled people. **Thus, its R&D expenditures in this area represent only 0.2 percent of its income transfer payments. By comparison, the Government's total health care R&D accounts for about 2 percent of its total health care costs.**

Private sector involvement in R&D is difficult to characterize or quantify. The companies and organizations that conduct R&D range from multibillion dollar companies to small businesses to nonprofit organizations, associations, and disease-specific foundations. Often, these companies and organizations are the primary actors in the development, delivery, and purchase of new technologies for their constituent groups. The R&D funds used may come from the companies and organizations themselves or from the Federal Government. **Debate continues to surround the issues of how much R&D is enough, who should do it, and who should benefit financially from the complex interaction of private, public, and nonprofit-sponsored research efforts.**

Despite problems, disability-related R&D is characterized by innovation. Given sufficient funding and an effective organization of efforts, the predicted "explosion" in relevant technologies could become reality. Advances in solid-state electronics, other communications/information developments, new alloys, microcomputer-aided movement (e.g., of artificial limbs), and biomedical knowledge, including neurochemistry, are already producing dramatic new possibilities. The future may see an acceleration of technological developments. Some advances (e.g., writing aids for physically disabled children) may have great value; others may turn out to be useless. Most important, though, is planning for and identifying the appropriate ways to evaluate, distribute, and use the breakthroughs.

Evaluation of technologies involves a broad spectrum of activities and a number of criteria. Safety, efficacy, feasibility, and profitability are the criteria often used first in evaluation efforts. Criteria that follow include effectiveness, reliability, cost, repairability, convenience, affordability, esthetics, consumer satisfaction, patent protection, legal impacts, liability concerns, accessibility, economic impact, reimbursement status, social implica-

tions, cost-effectiveness determinations, and ethical concerns. However, these important criteria are rarely, if ever, applied consistently to new technologies for disabled people in the public or the private sectors.

There is, however, no shortage of agencies, organizations, and universities interested in the various issues surrounding the evaluation of technologies. The level of the Federal effort in terms of money spent on evaluation efforts is impossible to determine fully. The lead agency in evaluation of technologies for disabled people is NIHR. Evaluation research supported by NIHR is conducted along with basic and applied research and technology development at the various NIHR-funded research centers. In theory, evaluation research is an integral part of the R&D process. In reality, it is often done only in an oversimplified fashion or with inadequate funding. NIHR does support some evaluation of devices produced outside of its research centers. However, the problem is that there are not enough of these activities. The Food and Drug Administration (FDA), the National Bureau of Standards (NBS), and NIH are three other agencies that focus on evaluation of technologies at the Federal level, but their efforts do not meet the evaluation needs in the area of technology for disabled or handicapped persons. The private sector is also involved in the evaluation of technologies, particularly technologies that it develops or distributes.

OTA finds that the public-private sector partnership is inadequately designed to support fully useful evaluation efforts and that a coherent, adequately funded and focused program of evaluation is needed at all levels of diffusion and adoption of technology for disabilities.

Such a finding is particularly crucial in view of the possibility of an increase in the number of technological advances becoming available—e.g., communications devices and mobility aids.

Diffusion and marketing of technologies for disabled people require quite different methods and information than the R&D and evaluation efforts. The public-private sector interrelationship is particularly complex. In the disability field, models of diffusion and marketing in the general health care system and of diffusion of innovations in the private sector—which are not necessarily complementary—are often at work simultaneously.

There are a number of successes in the diffusion and marketing of technologies that have been directly related to Federal efforts to bring a product developed under a Federal R&D program to private manufacturers for mass marketing and distribution. VA, NASA, and NIHR are lead agencies for these successes. However, such successes appear to be the exceptions. There are a number of reasons: the disability market population is ill-defined; the economic status of users is often far below the median; technologies often do not appear viable from a strictly "market" perspective, resulting in a lack of private interest in their production; product liability is often perceived by manufacturers to be a problem; and, especially, the systems for reimbursement of devices sometimes provide disincentives to the marketing of certain types of technologies. Two additional issues in this area are the problem of rapidly changing technology and the need to involve consumers to assure that marketing efforts are effective.

13

The use of technologies by disabled people appears to depend primarily, but certainly not entirely, on the public and nonpublic programs for which the individuals users are eligible. This is partly because many disabled people have lower than average earnings and partly because the variety of programs that exist are the primary source of information on available technologies. Through their affiliation with these programs and services, users either receive technologies directly, have them financed, or learn about them.

Although there are over 100 different Federal programs serving disabled people, the majority of public services are in the form of: 1) income maintenance, 2) health and medical care, 3) social services, 4) educational services, and 5) vocational rehabilitation and independent living. The greatest expenditures have been—and continue to be—for income maintenance, related transfer payments, and health and medical care.

The major income maintenance programs are Social Security Disability Insurance, Supplemental Security Income, VA pensions for nonservice-connected disabilities, and VA compensation for service-connected disabilities. Individual beneficiaries of these programs receive cash payments with no restrictions on their use. The programs influence the use of technologies not only because they provide the funds to purchase the technologies, but also because they establish eligibility for health, medical, and vocational-related services and technologies.

The major publicly financed health and medical care programs serving disabled people include Medicare, Medicaid, and VA medical services. The use of technologies is significantly affected by the amount of funds provided by these programs, either to individuals or providers, by the methods used to authorize payments, and by the organization of the provision of services. Policy issues that affect eligible Medicare and Medicaid recipients include what technologies are covered and how are those decisions made, what types of professions and institutions are recognized as providers, what amount is reimbursed for the cost of covered services, what technologies are determined to be medically necessary, and what effects the Medicare and Medicaid programs on the type and location of services to disabled beneficiaries.

The prime social services programs that serve disabled persons are those authorized under title XX of the Social Security Act and the developmental disabilities program authorized under the Developmental Disabilities Assistance and Bill of Rights Act. Under these programs, a wide range of technologies are directly provided to disabled people. Thus, the major issue affecting the delivery and use of technologies is the determination of eligibility for these programs (and currently, whether and in what form these programs and others will continue to exist).

The two largest education programs for disabled people are authorized under the Education for All Handicapped Children Act and the Vocational Education Act. If necessary for receipt of services under these programs, devices may be funded. The programs are more important, however, for

Photo credit: Courtesy of Phonic Ear, Inc., Mill Valley, Calif.

Aiding in preparing employment and carrying out job functions has always been one of the prime uses of technologies for disabilities. This photograph shows a woman using the Phonic Mirror Handivoice to communicate with her fellow workers. The Handivoice speaks the words which the person manually enters into it

preparing disabled people to use technologies and for providing information on what is available. The vocational rehabilitation and independent living programs authorized under the Rehabilitation Act directly provide technologies to eligible recipients for use in the workplace or to live outside of institutions (in the case of severely disabled individuals).

Although the availability of public funds in support of public policies has greatly shaped decisions in the private sector, nonprofit and for-profit private organizations are usually the actual providers of services under public programs. In addition, they provide services and funding not covered

by the public programs. Private insurance companies provide income maintenance, although the total amount is much less than what the public programs provide. Health and medical care are also provided: device technologies are funded using criteria similar to the public programs'.

Several issues, related to the public programs in general, affect the use of technologies by disabled people. They include: 1) the degree to which services and funding are coordinated from program to program or are consistent from State (or region) to State (or region); 2) the effect, on coordination and consistency, of the methods for determining eligibility; 3) the extent of the gaps in eligibility for services under public and nonpublic programs; 4) the degree to which maintaining rehabilitative device technologies is difficult or costly; 5) the degree to which consumers are effectively involved in services delivery; and 6) the shortage of rehabilitation providers.

OTA's examination of the current system of disability-related research, development, evaluation, diffusion, and use finds that the system suffers from a number of significant weaknesses. The system is, or could be, capable of a great deal more.

Information on available technologies is currently disseminated through publicly financed or publicly operated programs for disabled people. Information is often fragmented, since many of the programs cover discrete subject areas and are uncoordinated. **Strengthened information dissemination in a coordinated fashion is urgently needed.**

Providing disabled individuals with the advantages and opportunities provided by technologies requires the resolution of several policy issues. One issue is: What types of providers are most appropriate to match possible technologies with a potential user? That is, who shall be responsible, in cooperation with the user, for identifying possible technologies, selecting a technology, fitting it to the specific user, and training the user in its use?

Resource Allocation

The development and use of technologies for disabled persons are greatly affected by available resources and the ways in which they are allocated. In fact, all decisions about the development and application of such technologies are ones of resource allocation. Efforts to improve resource allocation must take into account the incentives and controls currently operating on the development, evaluation, diffusion, and use of technologies. They must also examine the "fit" between the intentions of policymakers to assist disabled people (create opportunities for disabled people to help themselves) and the actual assistance afforded by the available resources and the rules governing their allocation.

Effective resource allocation must take into account a number of current issues in the disability-related area. For example, to what degree should definitions of disability and handicap used in Federal programs focus on people's abilities as well as disabilities? An increased concentration on abilities could lead to the expenditure of a greater proportion of resources to

alter aspects of the environment that turn disabilities into handicaps. Another example of a current issue in resource allocation is the extent to which the Government should encourage and financially support independent living and the involvement of people with disabilities in pertinent actions such as evaluation of technologies or the determination of the types of personnel who will prescribe or fit technologies.

Other issues have to do with the types of outcomes sought in allocating resources, the degree to which society and other decisionmakers support the development and application of technologies to prevent disability, the influence of an increasingly aged population has on resource allocation, and the proper role and use of analytical techniques in allocation decisionmaking.

BRIEF POLICY OPTIONS

A large number of factors affect the success of technological applications in the area of disabilities. OTA's policy is to provide Congress with a series of alternative actions and discussions of the possible consequences of implementing them. The options in the full report are organized by issue area. The following presents brief statements of the issue areas and related policy options. The options are not mutually exclusive.

Production, Marketing, and Diffusion of Technologies

ISSUE 1

How can the Federal Government increase the probability that technologies will reach the people who need and desire them?

In as many cases as possible, commercial viability should be one of the goals sought in technology development. A critical issue is how to alter the currently inadequate state of marketing efforts and processes.

The production, marketing, and diffusion of technologies are most often private sector activities, and yet a number of factors work against that sector's willingness and ability to engage in them. R&D organizations have typically placed a low priority on production, marketing and diffusion activities. Also, the difficulty in projecting the markets for disability-related technologies increases the risks of a commercial venture, as do the often small populations in question. Many disabled individuals traditionally have had low average earnings or funds at their disposal. The reimbursement policies of the Federal Government and the States also contribute to the uncertainties of the marketplace for a firm considering the production of a technology.

OPTION 1A

Congress could amend current legislation to create a consistent and comprehensive set of fiscal and regulatory incentives encouraging private industry to invest in the production and marketing of disability-related technologies.

Fiscal incentives are created by policies, such as taxation policy, to allow private investors and firms to make more reliable estimates of potential returns on investment. Regulatory incentives seek to accomplish the same objectives as fiscal incentives but do so through methods less directly connected to financial factors, including patent and licensing policies. Another example would be changes in the penalties for noncompliance with Federal regulations regarding the hiring of disabled people or the provision of appropriate technologies to disabled people. This type of incentive would increase the demand and therefore the potential market for technologies.

One benefit of implementing this option is a potential increase in revenues to the Federal Government as a result of the larger corporate taxes paid by firms and the increased taxes paid by disabled people using technologies that allow them to lead more productive lives. On the cost side, revenues would be reduced by the amounts of any tax reductions embodied in the fiscal incentive structure. Yet Federal costs would be diminished by the reduction in funds spent on income transfer and health insurance payments. Also, a nonmonetary benefit of this option would be the increase in well-being of the disabled people who would benefit from receiving helpful technologies.

OPTION 1B

Congress could legislatively charter a private organization to provide marketing and production-related services to both the private and the public sectors.

Congress has occasionally granted an official charter to a nonprofit organization recognized to serve the public welfare. The initial funds for such an organization would come primarily from the nonpublic sector, with perhaps a small startup grant from the Government. After startup, however, it would be expected to operate on its own revenues.

The goal of the organization would be to provide technical assistance, analysis, and other services related to the production, marketing, and diffusion of disability-related technologies. Tasks performed in return for fees could include preparation of marketing surveys and strategies for private firms, and development and management of demographic and product data sets. The organization could also serve as a liaison between firms or Government agencies and ultimate consumers.

Two potential advantages of the proposed organization are that it is designed to carry out an important and currently inadequately performed function and that it is located in the nonpublic sector. Potential disadvantages lie in the possibility of conflict of interest and in the difficulty of the tasks assigned to the organization.

OPTION 1C

Congress could establish a joint public-private corporation to provide marketing and production-related services to both the private and the public sectors.

This option would have similar goals to the previous one and seek to accomplish them through the same types of tasks. Instead of the legal authority of a private corporation with official recognition as in option 1B, though, this option would establish a quasi-governmental entity. Analogous organizations are the Overseas Private Investment Corporation, the Tennessee Valley Authority, and the Federal National Mortgage Association. In setting up any such organization, public interest services can be performed using primarily private funding and managerial techniques.

OPTION 1D

Congress could mandate the collection of market-related demographic data by an interagency group led by the Bureau of the Census.

This option might reduce some of the uncertainty that accompanies the decision to develop or market a product by producing demographic data divided by types of functional limitations. It would also be useful to the public sector in setting research priorities and allocating funds for the applied engineering and diffusion stages of technology's lifecycle.

The cost of this option would vary considerably, depending on how extensively the current survey techniques and activities of the Bureau of the Census would have to be modified or expanded. It might be possible to create a mechanism whereby the private sector, including industry, advocacy groups, and foundations, could contribute funds to the effort. Another dimension along which costs would vary is the extent to which new data are collected as opposed to old data analyzed to provide new answers.

Involvement of Disabled People and Other Consumers

ISSUE 2

How can policies and programs be designed to encourage or assure the effective involvement of disabled people and other consumers in the development and delivery of technologies? In addition to providing information, consumers should themselves be part of advisory and policymaking bodies to the maximum extent feasible.

In theory, assuring maximum effectiveness, efficiency, and relevance in the development and application of technologies requires the extensive involvement of those who will use the technologies—the consumers. In practice, there is relatively little involvement. There is no "correct" amount of consumer involvement, and there is no easy way to achieve effective involvement. Consumer involvement is frequently discussed, however, and everyone seems to believe in the concept,—yet few satisfactory schemes or actual actions to improve the situation exist.

OPTION 2A

Congress could mandate formal consumer involvement in any or all Federal programs or federally funded programs related to the development and use of technologies.

Congress has already mandated consumer ("handicapped persons") involvement through several Federal laws. The individual planning processes required by several Federal laws, for example, are designed to involve disabled people or their parents or other representatives in decisions about education or rehabilitation. Under this option, Congress could expand the formal, statutorily based, requirements for the participation of disabled people in areas of policy development and program implementation, including setting research priorities, evaluating grant and contract proposals, evaluating reports of progress on existing grants and contracts, and reviewing technologies for inclusion in reimbursement and purchase lists.

In general, this option could involve a program-by-program review to determine which programs could use the various mechanisms for establishing or expanding consumer involvement. Consideration should be given wherever possible to the use of flexible mechanisms—e.g., combinations of advisory panels, staff hiring, and contracts with consumer groups—to make involvement as effective as possible.

OPTION 2B

Congress could mandate an office of consumer involvement to monitor and provide assistance to other offices dealing with technologies, and Congress could encourage all relevant agencies to expand consumer involvement.

Instead of legislatively mandating consumer involvement in specific instances, Congress could clearly encourage various agencies to expand their consumer involvement activities through oversight hearings, committee reports, and other means. This option provides the advantage of flexibility—flexibility to change as conditions change over time and as data on the performance of involvement methods become available.

The obvious disadvantage of this option relative to the previous one is the difficulty of gaining voluntary compliance by the agencies. Mandating the creation of an office of consumer involvement would be a step to lessen this disadvantage. The proposed office could coordinate, monitor, evaluate, provide technical assistance to, and report on the involvement of disabled people in Federal activities.

OPTION 2C

Congress could encourage agencies to increase consumer involvement activities.

If Congress wishes to signal a concern about the inadequate amount and quality of consumer involvement activities, it could do so through mechanisms less formal than legislation. These mechanisms include, as listed above, oversight hearings and records of hearings, and language in committee reports accompanying related legislation.

Research, Development, and Evaluation of Technologies

ISSUE 3

How can R&D activities be organized and funded to produce knowledge, techniques, or devices that serve the needs of disabled people and relevant providers in accordance with the magnitude of various problem areas and opportunities? How can evaluation of present and emerging technologies be organized to provide consumers, providers, and policymakers with adequate information?

Funding for both R&D and evaluation is quite low in relation to the amount spent on transfer payments and other services. For evaluation, though, a perhaps equal problem is the lack of recognition given to the potential contribution of evaluation to decisions about the appropriate application of technologies. The organization and directions of R&D and evaluation also contribute to the inadequate number of useful technologies from these activities. The peer review systems in effect are not well organized. Inadequate attention is paid to what will happen to the results of R&D once that stage is completed. The constraints and demands of marketing, production, and consumer acceptance and preferences continue to play a relatively small part in the R&D process, though that situation seems to be changing slowly.

OPTION 3A

Congress could mandate that consumers and production and marketing experts be represented on R&D panels and evaluation panels.

This option explicitly recognizes that considerable involvement of the people and organizations who will play a major role in the subsequent usefulness and diffusion of technologies should take place early in the processes of R&D and evaluation. Its implementation would require extensive thought on the most effective ways of avoiding tokenism and conflict-of-interest situations for private industry. Yet many aspects of the R&D and evaluation processes are amenable to experienced consumer input. Consumers might inject a degree of reality to the setting of R&D goals and priorities; evaluation criteria might be set to more closely resemble the list of factors that lead to a technology's successful application.

Production and marketing experts could help the R&D process in several ways. For example, the simple presence of such people on panels could remind researchers and policymakers that the end result of R&D is supposed to be (in most cases) useful and cost-effective techniques and devices. Also, their experience and expertise would allow them to make suggestions relating to the evaluations that are necessary and the technological characteristics that should be sought.

Theoretically, no congressional actions are necessary for the adoption of this option. If Congress finds that it is a desirable option, however, and the executive branch agencies do not implement it on their own, Congress could amend relevant laws to mandate that R&D-related peer review and other advisory groups have such representation.

OPTION 3B

Congress could mandate demonstration projects for the awarding of "production stage" grants or contracts early in the R&D process.

The objective of this option is to assist R&D efforts in the development of technologies that will be effective and will successfully reach their market. Small grants or contracts to nonprofit or profit-seeking organizations to analyze the potential market and to develop plans for the efficient production and diffusion of specific technologies may help. This option is oriented to only a demonstration effort because of the many questions that exist concerning the effectiveness of such a mechanism.

One method of implementing the demonstration would be to select through a competitive process a firm that is interested in the marketing rights, for a specified time or area, for a particular technology. That firm would use the contract funds to examine the most efficient ways to produce the technology under development.

OPTION 3C

Congress could appropriate specific increased funds for evaluation of technologies.

This option addresses the relatively low level of funds and activities currently existing in the disability area. Although economic realities naturally affect the viability of this option, it is important to remember that the current level of funding for evaluation is extremely low—yet the number of technologies being developed is increasing constantly and many are in need of evaluation. Some of these may produce dramatic effects, others may turn out to be useless, but most will produce benefit under certain conditions—i.e., when applied appropriately in relation to their costs and risks. An increased amount of funds will be needed to adequately assess these new technologies as well as existing ones.

OPTION 3D

Congress could conduct oversight hearings with the Department of Education to determine why the dissemination of information on technologies remains inadequate.

OTA finds that the amount, usefulness, and accessibility of information on the characteristics, availability, and performance of technologies are not meeting the needs of users or potential users. A partial explanation is that the National Rehabilitation Information Center is relatively new, and its ABLEDATA system is even newer. Also, these activities have not had significant amounts of funds appropriated.

Before any specific legislative actions are taken, a number of questions could be addressed in oversight hearings. Such hearings could be designed to bring out more clearly the reasons for the current situation and the administrative reactions to that situation. An example of questions that could be explored in oversight is: Why have agencies, especially in the Department of Education, oriented their dissemination activities to professional research institutions and similar clients?

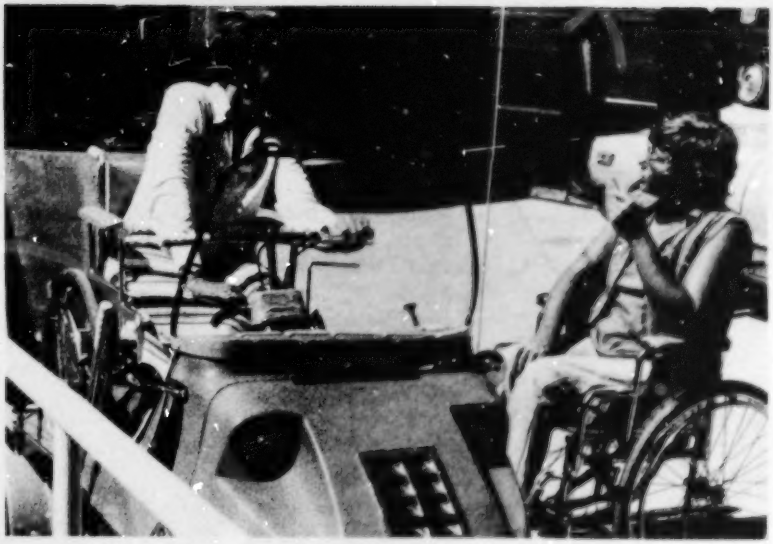

Photo credit: Barry Corbet. Courtesy of North American Reinsurance Corp.

Imogene Dickey of Buffalo, Wyo., uses a wheelchair for mobility. She and the chair ride on a Chair-E-Yacht or, for longer distances, a ramp-equipped van

Financial Barriers to the Use of Technology

ISSUE 4

How can financial barriers to the acquisition of technologies by disabled people be reduced, within reasonable constraints? Can the levels and distribution of available funding be made more appropriate in relation to the level of the problems addressed?

Imperfections in the structure of delivery systems need to be minimized. Inadequate and sometimes illogical criteria for reimbursement or payment for technologies should be reviewed and, where appropriate, changed.

Despite eligibility for the public and nonpublic programs that may pay for technologies to assist them to function more independently and productively, a number of disabled people are denied funding for particular technologies which are clearly appropriate. A primary reason for the denial of funding is that the technologies in question are not strictly "medical" in nature and are therefore not considered "necessary." While most indigent disabled persons are eventually able to receive some assistance towards meeting their needs, acquisition of technologies in the period immediately following the onset of their impairment presents particular financial hardships.

OPTION 4A

Congress could establish a loan guarantee program with low interest financing (on an income-related sliding scale) to assist disabled people in device purchases.

This option would reduce or eliminate financial barriers to acquiring devices for individuals who have the capability to generate the funds to pay for the devices but who do not have the resources for the initial capital outlay. These loans could assist in the purchases of devices which, in turn, would assist the individuals directly or indirectly to function independently, work, and pay back the loan.

Pursuit of this option would likely involve a minimum of Federal dollars. The program could be State-administered, as is the program of federally guaranteed student loans for higher education. The interest subsidies could be provided either by the Federal Government directly or by the lending institutions with tax incentives to do so. A significant implication of this option is the public-private partnership likely to occur if it were implemented.

OPTION 4B

Congress could conduct oversight hearings on ways to change criteria for reimbursement under the Federal health insurance programs with respect to technologies for disabled people.

Disabled people eligible for coverage under one of the Federal health insurance programs are often denied payment for technologies which are not considered strictly medical in nature, although the technologies would improve the independence and productivity of their lives. The legislation for the programs does not expressly prohibit payment for "nonmedical" technologies such as communication, education, and rehabilitative aids. Instead, the denials usually occur at the State or regional level through regulation. This way, funds may be saved in the short term, but in the long term, a greater amount of total funds is expended in, for example, income maintenance payments or institutionalization expenses.

Hearings on methods to change reimbursement criteria would focus attention on the need to consider the implications of policies in one area on other related areas. Theoretically, the hearings should provide alternative criteria for expanded reimbursement and suggested regulatory changes to accomplish that objective which the Health Care Financing Administration and the States could then adopt. Congress could then hold oversight hearings at a later date to determine the effects of any adopted changes.

OPTION 4C

Congress could conduct oversight hearings on methods to improve health insurance coverage for persons leaving employment as a result of disability.

The objective of this option is to reduce the financial barriers to the acquisition of technologies during the period immediately following termination from employment due to disability. Most people who leave employment lose health and medical insurance coverage formerly provided by their employers. Since health and medical insurance programs are a primary source of funding for technologies for disabled people, Congress could investigate ways to close these gaps and examine the resultant benefits and costs to society of any administrative action implemented.

One method that might be covered in oversight hearings is the provision of Medicare coverage during the 29-month period that individuals must wait for Federal Disability Insurance. Another method that might be covered is the provision of incentives to employers to provide health and medical insurance coverage to their terminated employees for 12 to 29 months following termination for disability-related reasons. Unless changes in the criteria for reimbursement under the Federal health insurance programs are pursued as discussed under the previous option, there is likely to be an inefficient expenditure of dollars under any program arising from these hearings as long as appropriate technologies are not covered.

Personnel Issues

ISSUE 5

How can Federal policies assure an adequate number of well-trained personnel at all stages of the development and use of technologies? Systems for R&D as well as delivery of services should provide incentives for the cost-effective use of these personnel.

Although the actual number of professionals (disabled and nondisabled) working to develop and apply technologies to disabled people has increased dramatically over the last 40 years, there remains a shortage in a number of key areas. First, there are too few rehabilitation researchers and rehabilitation engineers. Second, there are too few allied health professionals, including physical and occupational therapists, orthotic and prosthetic technologists, speech therapists, and rehabilitation counselors. Although the size of these shortages is difficult to quantify, legislation such as the Education for All Handicapped Children Act, as amended, has served to increase the demand.

Finally, there is a shortage of rehabilitation physician specialists. Under the current reimbursement system, this shortage is a key one, because it is often the physician who must prescribe a technology for it to be funded. Yet the physician is not always the appropriate provider to prescribe the technology, particularly if the technology is not medical in nature.

OPTION 5A

Congress could appropriate funds for the training of increased numbers of disability-related personnel, including rehabilitation engineers, rehabilitation medicine physician specialists, and allied health professionals.

The objective of this option is to alleviate the shortage of providers. Schools eligible to receive the funds under this option would include schools of engineering with specific programs for rehabilitation engineering, medical schools that sponsor residency programs in rehabilitation medicine, and schools for allied health professionals. An alternative to training more rehabilitation medicine specialists is training physicians in other specialties to become "managers" of the rehabilitation of disable clients.

OPTION 5B

Congress could encourage volunteer participation in assisting disabled people by modifying tax incentives related to volunteer expenses and charitable contributions.

This option suggests the use of volunteers to perform some of the functions normally provided by professionals, to enhance the services provided by professionals, and to assist in implementing existing legislation that has, to date, not been appropriated enough funds for full implementation (e.g., the Education for All Handicapped Children Act). Although "volunteer participation" suggests that no compensation is provided, the incentive of reduced taxes is known as a relatively inexpensive method of providing compensation. This option assumes that the provision of such "compensation" will increase the supply of volunteers.

OPTION 5C

Congress could mandate the funding of demonstration projects to test reimbursement for technologies under Federal health insurance programs by the types of skills provided rather than by the types of providers.

This option is in response to OTA's finding that those providers who are permitted by the structure of delivery and reimbursement systems to prescribe technologies for disabled people may not always be the most appropriate ones to do so. In these instances, a client may not receive the proper assistance, or the skills of several providers (those able to prescribe and those unable to) may be employed at more expense and loss of efficiency than necessary or desirable. Another problem is that services necessary for the proper use of prescribed technologies are often not reimbursed under the Federal health insurance programs (see option 4B) if they are not provided by a physician and are therefore not provided. A program of demonstration projects under the Medicare and Medicaid programs is proposed under this option in recognition of the untested status of this potentially helpful solution. Congress might want to limit the types of services eligible for the program in its authorization of the project.

NOTE: Copies of the full report "Technology and Handicapped People" can be purchased from the Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402.

General Information

Information on the operation of OTA, the nature and status of ongoing assessments, or a list of available publications may be obtained by writing or calling:

Public Communications Office
Office of Technology Assessment
U.S. Congress
Washington, D.C. 20510
(202) 226-2115

Publications Available

OTA Annual Report.—Details OTA's activities and summarizes reports published during the preceding year.

List of Publications.—Catalogs by subject area all of OTA's published reports with instructions on how to order them.

Press Releases.—Announces publication of reports, staff appointments, and other newsworthy activities.

OTA Brochure.—"What OTA Is, What OTA Does, How OTA Works."

Ongoing Assessments.—Contains brief descriptions of assessments presently under way with estimated dates of completion.

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